



## EDITORIAL

# Pre-implantation genetic diagnosis (PGD): The spectre of *eugenics* or a “no brainer”

On Wednesday the 10th of May 2006, the British Human Fertilisation and Embryology Authority (HFEA) gave the go ahead for pre-implantation genetic diagnosis (PGD) for the selection of embryos free of the mutations that predispose to breast or colo-rectal cancer. The hysterical over reaction of some sections of the press and the television studios was predictable. On the one hand we had shrill warnings that this was the slippery slope to “eugenics” and on the other hand we had members of affected families saying that the decision was a “no brainer”. Let me deal first of all with this reaction quickly before getting bogged down in what is a very complex ethical and biomedical debate.

The tiresome morsel of American jargon, “no brainer”, has slipped into common English usage quite recently and appears to have been adopted by those who have no valid opinions of their own. I suppose it stands in for “that which is self-evident”, amongst English speaking people. I heard it used in a television interview with a woman in her early forties, carrying a BRCA1 mutation, a member of an extended family with a strong family history of breast and ovarian cancer. What I found so grotesque about that statement apart from the mutilation of my mother tongue was the fact that if PGD had been available one generation earlier, she would not have been here to offer up her opinion. She might indeed have the right, after extensive counselling, to decide for herself to go through the rigours and expense of IVF and PGD, but to suggest that the rightness of that decision was self-evident, trivialises the issue (Fig. 1a and b).

Now let us try and get to grips with slippery slopes and eugenics. The term “eugenics” was coined by Francis Galton (1822–1911). He was an English scientist who studied heredity and intelligence and happened to be a cousin of Charles Darwin. Erasmus Darwin was Francis Galton’s maternal grandfather and also Charles Darwin’s paternal grandfather, so Galton was indeed fortunate to have been born into a family whose genetic pool included members of the Wedgwood and Keynes families. Galton defined his new word this way:

*“Eugenics is the study of agencies under social control that may improve or impair the racial qualities of future generations, whether physically or mentally.”*

In 1905, he wrote about the three stages of eugenics, first an academic matter, then a practical policy, and finally that “it must be introduced into the national consciousness as a new religion.” He described his ideas in an article entitled “Hereditary Character and Talent” published in 1864,<sup>1</sup> which expressed his frustration that no one was breeding a better human race:

*“If a twentieth part of the cost and pains were spent in measures for the improvement of the human race that is spent on the improvement of the breed of horses and cattle, what a galaxy of genius might we not create! We might introduce prophets and high priests of civilization into the world, as surely as we can propagate idiots by mating cretins. Men and women of the present day are, to those we might hope to bring into existence, what the pariah dogs of the streets of an Eastern town are to our own highly-bred varieties.”*

What is so chilling about reading these ramblings of an old Victorian bigot one hundred years later, is the fact that Adolf Hitler and the third Reich attempted to apply these principles in practice with mass sterilisation of inmates of mental asylums and undesirable non-Aryans as a prelude to mass murder.

I’m pretty sure that the HFEA does not have in mind that we should start building a master race of blond, blue eyed, athletic geniuses but is their endorsement of PGD to select out embryos predetermined to develop cancer in young adulthood the first step down a slippery slope towards a Galtonian Utopia. I think not. For a start I don’t subscribe to the “slippery slope” principle in ethics debates. This presupposes that there is a line of ethical principle that must never be crossed that is viewed from a point on the moral high ground. One step down, one concession, one turning of a blind eye and society loses its footing sliding



**Figure 1** (a and b) Eugenics or no brainer? Is the HFEA right to move forward with PGD for the selection of embryos free of the mutations that predispose to breast or colo-rectal cancer?

downwards into the ethical abyss. This as you see is argument by analogy. We have already made concessions in selecting babies. For example amniocentesis is commonly used before aborting foetuses with X-linked haemophilia or Down's syndrome. This technique can be abused for sex selection but that abuse is covered by law. A recent high-profile case in India ended when a gynaecologist who profited by aborting female foetuses was given a stiff jail sentence. No doubt the problem is rife in China where there is a one-child policy but in this example, sex selection is the consequence of social engineering and not the reverse.

Furthermore PGD is already available for families bearing the gene for cystic fibrosis, Tay Sachs disease, Huntington's chorea and thalassaemia; all dreadful diseases with early age onset. This as far as I know has never been associated with a slide down the slope of ethical compromise. So what makes the new ruling so controversial? In screening embryos for the BRCA mutations that predispose to breast cancer and hereditary polyposis coli (HPC) the word is *predispose*. In other words not inevitable. For example BRCA2 has about a 50% penetrance for breast cancer and breast cancer can be prevented by prophylactic mastectomy for all cases with BRCA mutations. In the same way colo-rectal cancer can be prevented in HPC by prophylactic colectomy. These are not trivial interventions but have to be weighed up against the very nature of personhood.

I can see how PGD could breed out the faulty gene in the fullness of time and spare mothers from the guilt and anxiety of passing it on but I can also understand the argument that you might be destroying an embryo, albeit only eight cells in total, that might lead to an adult of unknown potential who might lead a full and productive life. At the same time I know that left to nature about half such embryos at this stage of gestation would spontaneously abort or as Gillian Lockwood, Chairman of the British Fertility Society's ethical committee so eloquently put it: "half the eggs fertilised naturally don't become babies and we are not in a perpetual state of mourning". So can I take a position on this? Well like all of us it's only when it's up front and personal that the hypothetical debate becomes a matter of serious decision-making.

As chance would have it at the very time I was pondering these issues a front-page article appeared in the Daily Telegraph of May 15th entitled "We had to go abroad to get our baby screened". Below that was a lovely family photograph of Dr. Mandy Baum (my niece!), her husband, her oldest son affected with tuberous sclerosis (TS), her second son without the inherited gene and her baby son selected successfully to be free of TS by IVF and PGD at a clinic in Brussels. Of course I knew this was in the offing but the timing was remarkable and when I think back about all the suffering and anguish Mandy and her husband Phillip went through to reach this happy outcome I had no doubt it was the right choice for them.

Last year our family went through another period of crisis when my sister agreed to be tested for a BRCA mutation because of the familial pre-disposition to breast cancer, for the sake of her four daughters, another clutch of nieces, fortunately she tested negative. Had she had tested positive I don't think I would have wanted the gene bred out of the family because I'm confident that in such cases breast cancer will one day be preventable and in due course curable. Furthermore for all we know that breeding out one undesirable gene might be associated with the inadvertent loss of a desirable gene from the same pool.

Those are my opinions but in the end the technology is here to stay, it cannot be un-invented and like all technology can be used for good or for evil. What is needed is control and mature debate. It's neither *eugenics* nor a *no brainer*.

## Reference

1. Galton F. Hereditary character and talent. *MacMillan's Magazine* 1864;11:157–66.

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